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In Support of Raised Bill 5013**

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Thank you for this opportunity to address the Committee regarding Raised Bill 5013.

Advocacy for Patients with Chronic Illness, Inc. represents consumers with complex health care needs, many of whom do not have, and cannot find, insurance due to pre-existing conditions. The Affordable Care Act (the ACA) is intended, at least in part, to change that.

The creation of Exchanges – marketplaces where consumers can shop for health care, as well as be screened for Medicaid, CHIP, and advance premium tax credits or subsidies – is central to the ACA. In designing Exchanges, though, many decisions have been left to the States. Thus, the membership of the Exchange Board is critical; the Board will make many key decisions and recommendations to the General Assembly – including, for example, whether to have a Basic Health Program and what to include in the essential health benefits package. These decisions will impact the lives of everybody who uses the Exchange – indeed, ultimately, everybody in Connecticut. But nobody will be affected more directly than people with disabling chronic illnesses.

It is for that reason that the federal government, in the preamble to the proposed regulation creating Exchanges, stated that “Exchanges are intended to support consumers . . . and as such, the majority of the voting members of governing boards should be individuals who represent their interests.” Thus, the Obama Administration cautioned against allowing Exchanges to be dominated by the insurance industry, brokers or health care providers, as our General Assembly wisely legislated against.

However, it is not enough to exclude certain groups from serving on the Exchange Board; we must also include as Board members people who have an intimate knowledge of the obstacles people with chronic illnesses and other disabilities face not only in finding insurance, but in obtaining coverage for the tests and treatments that they need, in communicating with insurance companies, in understanding our insurance benefits, and in accessing health care.

Thus, although we have no doubt that the members of the Exchange Board are well-intentioned, they simply do not know what I know, see what I see, both as a patient myself, and as a lawyer for thousands of patients with chronic illness. Indeed, nobody who has not walked in the shoes of a patient with a complex health condition really understands the obstacles we face.

Without that understanding – without people at the table who themselves have encountered the obstacles that confront people with chronic illnesses – the Exchange Board cannot possibly make fully-informed decisions. Indeed, the Exchange Board already has received a final report from its consultant that recommends considering mechanisms such as prescription drug specialty tiers – something that could result in coinsurance ranging to over \$3,000 per month for medication that is needed to maintain our ability to function in the workplace, in the community, and at home. That same report, however, fails even to mention innovations that might reduce costs and improve our quality of care such as patient-centered medical homes. This report could not have been finalized in this form if there had been consumers on the Board.

Indeed, many crucial decision-makers already have recognized the importance of eliciting the input of people with chronic illnesses when considering issues that affect us. I personally have been called on repeatedly, as an expert in the obstacles facing people with chronic illnesses, to participate in conversations with the White House, HHS, DOL, and Treasury about health reform implementation. I have been invited to meet with the President's disability policy team to discuss the special nature of largely invisible, albeit often disabling, chronic illnesses. I have been asked to consult with one of the Nation's largest insurance companies to help them fully appreciate the problems consumers encounter in attempting to access care. All of those decision-makers have recognized that I have knowledge, information, and experience that is valuable to them because I live this experience every day. The State of Connecticut – this Committee and the General Assembly as a whole – should recognize that we patients bring something unique and important to the table, as well.

We consumers want the Exchange to succeed. Indeed, we desperately need it to do so. It is for that reason that we are fighting so hard to be included in the discussion. I sincerely believe that my voice or the voice of others like me must be heard if the Exchange is going to meet our needs. It is not enough to gather comments from consumers, or even to have a powerless advisory committee comprised of consumers; we must be at the table with a vote if our needs are to be addressed in a meaningful way.

In fact, I would strongly recommend that the Committee consider moving up the effective date of these changes to the Exchange Board. The staff of the Exchange is being hired now. The consultants are finishing reports now. Decisions will be made soon about critical aspects of the Exchange. It does not take from now until July to appoint two new members and give the Healthcare Advocate a vote. The General Assembly should pass this legislation immediately, effective immediately, to ensure that every decision made by the Exchange Board from here on in is made with the benefit of the knowledge and experience of consumers with complex health needs.

Thank you.